

DMH Satisfaction Survey Results

Consumer Satisfaction - 2000

Division of Mental Retardation and Developmental Disabilities - Family Directed Support

Introduction

Missouri's Family Directed Supports (MFDS) was established in July, 1998, by the Missouri Division of Mental Retardation and Developmental Disabilities as part of an overall system redesign initiative aimed at supporting families caring for a member with a developmental disability in their home. Incorporating the values and principles of family support, Missouri's Family Directed Supports emphasizes the responsibility and authority of families in planning, developing, and accessing the unique supports they need.

The survey looked at the impact of the Family Directed Support program on families. The purpose of the survey was to solicit opinions from participants as to how the program has affected their family. The second portion of the survey asked families to describe other issues or events that impact on their family's life. This report will describe the findings of the survey.

Methodology

All families that received services under the Family Directed Support program (818 families) were mailed survey forms. Two hundred fifty-five forms were returned, for a return rate of 31.2%.

Demographics of the Sample

The survey looked at the age of the family member who was receiving services, the relationship of the person who completed the survey to the consumer, and whether a Support Agreement had been approved or signed. There were many instances where the respondent did not complete the demographic information. The frequencies of these demographics will be presented.

Gender of Recipient

Families reported more males served (61.5%) than females (38.5%).

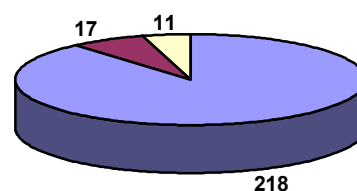
Racial Background

The majority of the families were Caucasian (88.6%). There were 17 families (6.9%) who were African American, and 11 families who noted an "other" racial background. (See Figure 1.)

Age of the Recipient

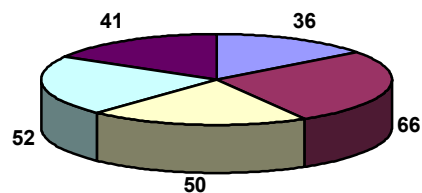
The age of the family member was listed on the form. When two family members' ages were listed, the oldest was used. The mean age was 17.98 years. Figure 2 presents the age distribution.

Figure 1. Racial Background



(9 Missing Cases)

Figure 2. Age of Recipients



(10 Missing Cases)

Satisfaction with Services

Overall both families in the regular Division of MR/DD sample and in the FDS (Family Directed Support) sample were satisfied with the services (means of 4.03 and 4.12 respectfully). Families in both groups were least satisfied with the timeliness of services. The highest satisfaction rating was in the item on the manner in which staff respect their cultural and ethnic background (See Table 1).

Table 1 - Satisfaction with Services (Part 1)

How happy are you . . .	Albany (MRDD only)	Albany (FDS only)	Central (MRDD only)	Central (FDS only)	Hannibal (MRDD only)	Hannibal (FDS only)	Joplin (MRDD only)	Joplin (FDS only)	Kansas City (MRDD only)	Kansas City (FDS only)	Kirksville (MRDD only)	Kirksville (FDS only)
1. with the people who are paid to support your family member?	4.67 (9)	4.12 (17)	3.56 (9)	4.19 (21)	4.25 (16)	4.75 (8)	3.92 (12)	4.15 (13)	4.29 (35)	4.31 (32)	4.08 (13)	4.29 (7)
2. with how much your family member's support staff know about how to get things done?	4.70 (10)	3.88 (17)	3.44 (9)	4.05 (21)	4.27 (15)	4.50 (10)	4.08 (13)	4.38 (13)	4.03 (34)	4.00 (33)	4.00 (13)	4.17 (6)
3. with how staff and/or case manager keeps things about your family member and his/her life confidential?	4.60 (10)	4.35 (17)	3.63 (8)	4.67 (21)	4.21 (14)	5.00 (10)	4.17 (12)	4.21 (14)	4.11 (35)	4.42 (33)	4.46 (13)	4.57 (7)
4. that your family member's plan has what he/she wants in it?	4.56 (9)	4.07 (15)	4.00 (8)	4.14 (21)	4.14 (14)	4.50 (10)	4.15 (13)	3.85 (13)	4.09 (34)	4.29 (31)	4.00 (11)	4.00 (7)
5. with how the case manager and support people are doing what your family member's plan says they should do?	4.60 (10)	4.06 (17)	3.67 (9)	4.14 (21)	4.40 (15)	4.60 (10)	3.92 (13)	4.14 (14)	4.08 (36)	4.03 (33)	4.08 (12)	4.29 (7)
6. that the staff who provide services to your family member respect his/her ethnic and cultural background?	4.83 (6)	4.44 (16)	3.89 (9)	4.63 (16)	4.43 (14)	4.80 (10)	4.00 (10)	4.75 (12)	4.38 (32)	4.42 (31)	4.36 (11)	4.20 (5)
7. with the supports and services that your family member receives from this Regional Center?	4.50 (10)	4.18 (17)	3.50 (8)	4.05 (21)	4.21 (14)	4.40 (10)	4.08 (12)	4.00 (14)	4.11 (35)	4.18 (33)	4.38 (13)	4.43 (7)
8. that services to your family member are provided in a timely manner?	4.70 (10)	3.73 (15)	3.44 (9)	4.00 (21)	4.13 (15)	4.50 (10)	4.23 (13)	3.86 (14)	4.12 (34)	3.94 (33)	4.15 (13)	4.29 (7)
9. with your family member's case manager?	4.70 (10)	3.94 (17)	4.00 (9)	4.25 (20)	4.33 (15)	4.67 (9)	4.23 (13)	4.43 (14)	4.47 (34)	4.44 (32)	4.31 (13)	4.43 (7)
The first number represents a mean rating. Scale: 1=Not at all satisfied . . . 5=Very satisfied. The number in parentheses represents the number responding to this item.												

Table 1 - Satisfaction with Services (Part 2)

How happy are you . . .	Poplar Bluff (MRDD only)	Poplar Bluff (FDS only)	Rolla (MRDD only)	Rolla (FDS only)	Sikeston (MRDD only)	Sikeston (FDS only)	Springfield (MRDD only)	Springfield (FDS only)	St. Louis (MRDD only)	St. Louis (FDS only)	Total State (MRDD only)	Total State (FDS only)
1. with the people who are paid to support your family member?	3.79 (19)	4.40 (5)	4.35 (17)	4.13 (24)	4.42 (12)	4.32 (22)	4.42 (26)	4.57 (7)	4.00 (66)	4.24 (74)	4.15 (234)	4.26 (230)
2. with how much your family member's support staff know about how to get things done?	3.47 (19)	3.60 (5)	4.19 (16)	3.73 (26)	3.92 (12)	4.17 (23)	4.42 (26)	3.86 (7)	3.94 (70)	4.02 (81)	4.03 (237)	4.02 (242)
3. with how staff and/or case manager keeps things about your family member and his/her life confidential?	3.76 (21)	3.80 (5)	4.25 (16)	4.20 (25)	4.64 (11)	4.50 (24)	4.47 (30)	4.43 (7)	4.27 (66)	4.43 (76)	4.24 (236)	4.43 (239)
4. that your family member's plan has what he/she wants in it?	3.45 (20)	4.20 (5)	4.29 (17)	4.00 (25)	4.36 (11)	4.30 (20)	4.39 (28)	4.13 (8)	4.14 (65)	4.10 (83)	4.13 (230)	4.13 (238)
5. with how the case manager and support people are doing what your family member's plan says they should do?	3.41 (22)	3.40 (5)	4.00 (16)	3.84 (25)	4.45 (11)	4.30 (23)	4.38 (29)	4.00 (7)	3.87 (61)	4.08 (83)	4.03 (234)	4.09 (245)
6. that the staff who provide services to your family member respect his/her ethnic and cultural background?	3.89 (9)	4.20 (5)	4.31 (13)	4.46 (24)	4.45 (11)	4.38 (21)	4.50 (26)	4.71 (7)	4.33 (69)	4.44 (64)	4.33 (210)	4.48 (211)
7. with the supports and services that your family member receives from this Regional Center?	3.45 (22)	4.00 (5)	4.35 (17)	3.88 (26)	4.27 (11)	4.30 (23)	4.30 (30)	4.14 (7)	3.85 (80)	4.08 (84)	4.03 (252)	4.12 (247)
8. that services to your family member are provided in a timely manner?	3.59 (22)	3.40 (5)	4.18 (17)	3.73 (26)	4.00 (12)	4.33 (24)	4.27 (30)	4.13 (8)	3.85 (78)	3.69 (83)	4.01 (253)	3.89 (246)
9. with your family member's case manager?	3.86 (22)	4.00 (5)	4.31 (16)	4.23 (26)	4.45 (11)	4.67 (24)	4.47 (30)	4.38 (8)	3.93 (76)	4.16 (83)	4.20 (249)	4.29 (245)
<p>The first number represents a mean rating. Scale: 1=Not at all satisfied . . . 5=Very satisfied. The number in parentheses represents the number responding to this item.</p>												

Satisfaction with Quality of Life

The families were most satisfied with safety in their home. Those in the FDS were least satisfied with the opportunity to make friends. The families in the regular Division of MR/DD program were least satisfied with what their family member did during his/her free time. (See Table 2).

Table 2 - Satisfaction with Quality of Life (Part 1)

How happy are you . . .	Albany (MRDD only)	Albany (FDS only)	Central (MRDD only)	Central (FDS only)	Hannibal (MRDD only)	Hannibal (FDS only)	Joplin (MRDD only)	Joplin (FDS only)	Kansas City (MRDD only)	Kansas City (FDS only)	Kirksville (MRDD only)	Kirksville (FDS only)
10. with how your family member spends his/her day?	4.55 (11)	3.41 (17)	3.56 (9)	3.76 (21)	3.53 (15)	4.60 (10)	3.85 (13)	3.79 (14)	4.22 (37)	4.06 (32)	3.75 (12)	4.00 (7)
11. with where your family member lives?	4.60 (10)	4.24 (17)	4.22 (9)	4.52 (21)	4.20 (15)	5.00 (10)	4.25 (12)	4.79 (14)	4.29 (35)	4.71 (31)	4.08 (12)	4.43 (7)
12. with the number of choices your family member has in his/her life?	4.44 (9)	3.27 (15)	3.56 (9)	3.81 (21)	3.85 (13)	4.50 (10)	3.92 (12)	3.50 (12)	4.03 (34)	3.79 (33)	3.58 (12)	4.14 (7)
13. with the opportunities/ chances your family member has to make friends?	4.67 (9)	2.71 (17)	3.44 (9)	3.37 (19)	3.93 (14)	4.30 (10)	3.83 (12)	3.69 (13)	4.03 (35)	3.58 (31)	3.83 (12)	3.71 (7)
14. with your family member's health care?	4.60 (10)	4.06 (17)	3.67 (9)	4.00 (21)	4.13 (15)	4.50 (10)	4.17 (12)	4.14 (14)	4.26 (35)	3.91 (32)	4.08 (12)	3.71 (7)
15. with what your family member does during his/her free time?	4.22 (9)	3.31 (16)	3.56 (9)	3.75 (20)	3.71 (14)	4.20 (10)	3.45 (11)	3.50 (12)	4.03 (36)	3.81 (32)	3.83 (12)	3.29 (7)
16. with the opportunities your family member has had during the last year to do something that he/she is proud of?	4.67 (9)	3.71 (14)	4.00 (9)	3.89 (19)	3.92 (12)	4.33 (9)	4.17 (12)	3.67 (12)	4.16 (32)	3.80 (30)	3.58 (12)	4.14 (7)
How safe do you feel ...												
17. your family member is in his/her home?	4.90 (10)	4.59 (17)	4.22 (9)	4.71 (21)	4.47 (15)	5.00 (10)	4.25 (12)	4.79 (14)	4.43 (35)	4.82 (33)	4.27 (11)	4.29 (7)
18. your family member is in his/her neighborhood?	4.90 (10)	4.24 (17)	4.11 (9)	4.38 (21)	4.46 (13)	4.10 (10)	4.17 (12)	4.64 (14)	4.26 (34)	4.27 (33)	4.36 (11)	3.86 (7)
The first number represents a mean rating. Scale: (how satisfied are you...): 1=Not at all satisfied . . . 5=Very satisfied. Scale: (how safe do you feel...): 1=Not at all safe . . . 5=Very safe. The second number represents the number responding to this item.												

Table 2 - Satisfaction with Quality of Life (Part 2)

How happy are you . . .	Poplar Bluff (MRDD only)	Poplar Bluff (FDS only)	Rolla (MRDD only)	Rolla (FDS only)	Sikeston (MRDD only)	Sikeston (FDS only)	Springfield (MRDD only)	Springfield (FDS only)	St. Louis (MRDD only)	St. Louis (FDS only)	Total State (MRDD only)	Total State (FDS only)
10. with how your family member spends his/her day?	3.77 (22)	3.00 (5)	4.20 (15)	3.41 (27)	4.50 (12)	3.91 (23)	3.97 (30)	3.88 (8)	3.95 (82)	3.76 (82)	3.99 (258)	3.78 (246)
11. with where your family member lives?	4.50 (22)	4.60 (5)	4.13 (16)	4.30 (27)	4.50 (12)	4.64 (22)	4.57 (28)	4.86 (7)	4.33 (82)	4.40 (81)	4.34 (253)	4.51 (242)
12. with the number of choices your family member has in his/her life?	3.45 (22)	3.80 (5)	4.13 (16)	3.31 (26)	4.09 (11)	3.55 (22)	3.97 (29)	3.57 (7)	3.90 (78)	3.49 (78)	3.90 (245)	3.60 (236)
13. with the opportunities/ chances your family member has to make friends?	3.64 (22)	3.40 (5)	3.94 (17)	3.48 (27)	4.09 (11)	3.35 (23)	4.07 (27)	4.00 (7)	3.91 (79)	3.05 (77)	3.94 (247)	3.34 (236)
14. with your family member's health care?	3.82 (22)	3.40 (5)	4.38 (16)	3.70 (27)	4.27 (11)	4.18 (22)	4.37 (30)	3.86 (7)	4.05 (74)	4.11 (83)	4.15 (246)	4.02 (245)
15. with what your family member does during his/her free time?	3.27 (22)	3.50 (4)	3.88 (17)	3.37 (27)	3.82 (11)	3.50 (22)	4.10 (29)	3.57 (7)	3.73 (79)	3.23 (81)	3.80 (249)	3.47 (238)
16. with the opportunities your family member has had during the last year to do something that he/she is proud of?	3.19 (21)	3.75 (4)	3.82 (17)	3.65 (26)	4.09 (11)	3.74 (19)	4.21 (24)	4.00 (7)	3.82 (78)	3.62 (76)	3.91 (237)	3.75 (223)
How safe do you feel ...												
17. your family member is in his/her home?	4.00 (22)	4.20 (5)	4.50 (16)	4.33 (27)	4.77 (13)	4.57 (23)	4.66 (29)	4.25 (8)	4.57 (84)	4.55 (85)	4.48 (256)	4.59 (250)
18. your family member is in his/her neighborhood?	4.05 (22)	4.00 (5)	4.56 (16)	4.30 (27)	4.70 (10)	4.43 (23)	4.59 (29)	3.75 (8)	4.32 (79)	4.14 (80)	4.37 (245)	4.23 (245)
<p>The first number represents a mean rating. Scale: (<i>how satisfied are you...</i>): 1=Not at all satisfied . . . 5=Very satisfied. Scale: (<i>how safe do you feel...</i>): 1=Not at all safe . . . 5=Very safe. The second number represents the number responding to this item.</p>												

Impact of the Program on Family Life

The family members were asked to rate how their life had changed in each of fifteen areas as a result of their participation in Missouri's Family Directed Support Program. The families were asked to rate this change on a five point scale (1=*a lot worse*; 2=*a little worse*; 3=*no change*; 4=*a little better*; 5=*a lot better*). Means were calculated for each of the responses as well as the frequency distribution of the responses.

Overall

One question asked how their family's life overall had changed. The mean for this item was 4.20. Forty-one percent of those who responded reported that their life was at least *a little better*. Also, approximately 41% of the respondents noted that it was *a lot better*. (See Figure 3.)

Family Functioning

Four items examined the ability of the family to function. These included (1) family's ability to do more together; (2) the stress in the family's life; (3) the family's ability to be more like other families; and (4) financial worries. Table 3 presents the results.

Table 3. Changes in Family Functioning

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean^a
Your Family's ability to do more together	-	6 (2.4%)	86 (34.5%)	91 (36.5%)	66 (26.5%)	3.87
The stress in your family's life	3 (1.2%)	19 (7.6%)	51 (20.3%)	104 (41.4%)	74 (29.5%)	3.90
Your family's ability to be more like other families	2 (0.8%)	7 (2.9%)	92 (37.6%)	90 (36.7%)	54 (22.0%)	3.76
Your financial worries	6 (2.4%)	14 (5.6%)	76 (30.5%)	83 (33.3%)	70 (28.1%)	3.79

^aScale: 1 = *a lot worse*.....5 = *a lot better*

The item with the highest mean was the stress in the family's life. This item showed a mean change of 3.90, indicating that it was *a little better* than before. The other items in this category were also slightly improved for at least 50% of the respondents. All of these items showed similar change.

The means for the respondents of each Regional Center were calculated. (See Table 4.) The range of responses was a mean of 3.33 to a mean of 4.40.

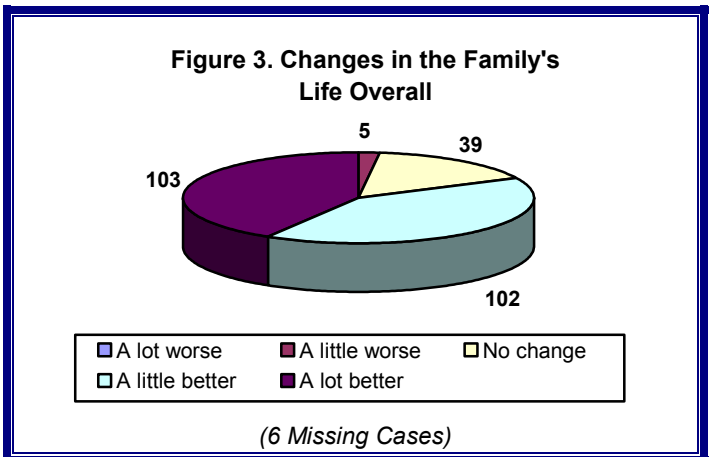


Table 4. Regional Center Means of Changes in Family Functioning

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your family's ability to do more together	3.76 (17)	3.50 (6)	4.40 (10)	3.94 (33)	3.64 (14)	3.88 (8)
The stress in your family's life	3.53 (17)	3.83 (6)	4.30 (10)	4.24 (33)	3.71 (14)	4.13 (8)
Your family's ability to be more like other families	3.75 (16)	3.80 (5)	4.40 (10)	3.84 (32)	3.43 (14)	4.25 (8)
Your financial worries	3.59 (17)	3.67 (6)	4.40 (10)	4.18 (33)	3.85 (13)	3.88 (8)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your family's ability to do more together	3.63 (27)	4.40 (5)	4.04 (25)	3.84 (83)	3.95 (21)	3.87 (249)
The stress in your family's life	3.52 (27)	4.20 (5)	4.04 (25)	3.86 (85)	4.00 (21)	3.90 (251)
Your family's ability to be more like other families	3.41 (27)	4.40 (5)	3.76 (25)	3.76 (82)	3.71 (21)	3.76 (245)
Your financial worries	3.33 (27)	3.20 (5)	4.04 (25)	3.82 (84)	3.33 (21)	3.79 (249)
^a Scale: 1 = a lot worse.....5 = a lot better						

Caring for Family Member

The survey looked at the ability of the family to care for the family member. There were two items that related to this category: (1) ability to care for family member; and (2) worries about family member's future well being (see Table 5 for the results).

Table 5. Changes in Caring for Family Member

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean^a
Your ability to care for your family member	3 (1.2%)	6 (2.4%)	52 (21.1%)	91 (36.8%)	95 (38.5%)	4.09
Your worries about your family member's future well being	8 (3.2%)	10 (4.0%)	88 (35.2%)	91 (36.4%)	53 (21.2%)	3.68
^a Scale: 1 = a lot worse.....5 = a lot better						

The families perceived at least a slight change for the better on the first of these items. For the item about caring for their family member, 38.5% noted *a lot better* situation now. For worrying about their family member's future well being, only 21.2% of the respondents noted a lot of improvement.

The means by Regional Center were calculated for changes in caring for family members.

Table 6. Regional Center Means of Changes in Caring for Family Member

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your ability to care for your family member	3.82 (17)	4.40 (6)	4.50 (10)	4.33 (33)	4.07 (14)	3.88 (8)
Your worries about your family member's future well being	3.41 (17)	4.00 (6)	4.30 (10)	3.82 (33)	3.71 (14)	3.88 (8)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your ability to care for your family member	3.58 (26)	4.20 (5)	4.24 (25)	4.11 (84)	4.10 (20)	4.09 (247)
Your worries about your family member's future well being	3.63 (27)	3.60 (5)	3.80 (25)	3.54 (85)	3.75 (20)	3.68 (250)
^a Scale: 1 = a lot worse.....5 = a lot better						

Families' Ability to Do Activities

The literature has often reported that families of individuals with developmental disabilities have more difficulty maintaining a social life. The survey looked at several items that related to this category. First was the family's ability to do things that they were unable to do before. The second related to the family's ability to get to know other people in the community. The third item focused on the family's level of inclusion in the community (see Table 7).

Table 7. Changes in the Families' Ability to do Activities

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean^a
Your ability to do things that you were unable to do before	7 (2.8%)	8 (3.2%)	73 (29.1%)	84 (33.5%)	79 (31.5%)	3.88
Your ability to get to know other people in your community	2 (0.8%)	5 (2.0%)	135 (54.4%)	63 (25.4%)	43 (17.3%)	3.56
Your family's level of inclusion in the community	2 (0.8%)	4 (1.6%)	137 (55.2%)	66 (26.6%)	39 (15.7%)	3.55
^a Scale: 1 = a lot worse.....5 = a lot better						

The Family Support Program had a larger impact on the families' ability to do things they were unable to do before than the other categories. Sixty-five percent of the respondents noted that this had changed for the better since participating in the program. The item that showed the least amount of positive change was the family's level of inclusion in the community. Here only 15.7% noted that it was *a lot better*.

Table 8. Regional Center Means of Changes in the Families' Ability to do Activities

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your ability to do things that you were unable to do before	3.71 (17)	3.50 (6)	4.50 (10)	4.09 (33)	4.07 (14)	3.88 (8)
Your ability to get to know other people in your community	3.65 (17)	3.33 (6)	4.40 (10)	3.58 (33)	3.43 (14)	3.43 (7)
Your family's level of inclusion in the community	3.53 (17)	3.17 (6)	4.60 (10)	3.53 (32)	3.21 (14)	3.25 (8)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your ability to do things that you were unable to do before	3.56 (27)	3.80 (5)	4.12 (25)	3.78 (85)	3.90 (21)	3.88 (251)
Your ability to get to know other people in your community	3.26 (27)	4.00 (5)	3.64 (25)	3.55 (84)	3.55 (20)	3.56 (248)
Your family's level of inclusion in the community	3.37 (27)	3.40 (5)	3.76 (25)	3.57 (83)	3.48 (21)	3.55 (248)
^a Scale: 1 = a lot worse.....5 = a lot better						

Family's Well Being

There were two items on the survey that related to the family's well being. One concerned their emotional well being and the other their physical health (see Table 9).

Table 9. Changes in the Family's Well Being

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean ^a
Your family's emotional well being	5 (2.0%)	11 (4.4%)	75 (30.0%)	98 (39.2%)	61 (24.4%)	3.80
Your family's physical well being	2 (0.8%)	10 (4.0%)	120 (48.2%)	70 (28.1%)	47 (18.9%)	3.60
^a Scale: 1 = a lot worse.....5 = a lot better						

The respondents noted a larger positive change in their emotional well being than in their physical health. The mean of the former was 3.80 with 63.6% noting a change for the better, while the latter mean was 3.60, with only 47% reporting this change.

Table 10. Regional Center Means of Changes in Family's Well Being

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your family's emotional well being	3.41 (17)	3.83 (6)	4.30 (10)	4.13 (32)	3.57 (14)	4.13 (8)
Your family's physical well being	3.47 (17)	3.33 (6)	4.30 (10)	3.82 (33)	3.64 (14)	3.43 (7)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your family's emotional well being	3.48 (27)	3.60 (5)	4.12 (25)	3.69 (85)	3.86 (21)	3.80 (250)

Your family's physical well being	3.41 (27)	3.40 (5)	3.68 (25)	3.57 (84)	3.48 (22)	3.60 (249)
^a Scale: 1 = a lot worse.....5 = a lot better						

Family Members' Well Being

The impact on the family members' well being was reported to be less than the impact on the family's well being (See Table 11).

Table 11. Changes in the Family Members' Well Being

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean ^a
Your family members' emotional well being	1 (0.4%)	9 (3.6%)	80 (32.1%)	98 (39.4%)	61 (24.5%)	3.84
Your family members' level of inclusion in the community	1 (0.4%)	7 (2.8%)	126 (50.8%)	70 (28.2%)	44 (17.7%)	3.60
Your family members' growth and development	1 (0.4%)	6 (2.4%)	72 (29.1%)	99 (40.1%)	69 (27.9%)	3.93
^a Scale: 1 = a lot worse.....5 = a lot better						

The families reported a positive change in regarding to the emotional well being of the family member, 63.9% noted a positive impact, as well as the family members' growth and development, 68% noted a positive impact. Most of the families reported no change occurring for the family members' community inclusion. Here, 50.8% of the families reported no change with an additional 3.2% reporting a negative impact.

Table 12. Regional Center Means of Changes in Family Members' Well Being

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your family member's emotional well being	3.65 (17)	3.83 (6)	4.20 (10)	4.18 (33)	3.86 (14)	3.75 (8)
Your family member's level of inclusion in the community	3.53 (17)	3.17 (6)	4.30 (10)	3.73 (33)	3.50 (14)	3.50 (8)
Your family member's growth and development	3.76 (17)	3.33 (6)	4.30 (10)	4.30 (33)	3.92 (13)	4.38 (8)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your family member's emotional well being	3.63 (27)	4.00 (5)	4.12 (25)	3.72 (83)	3.67 (21)	3.84 (249)
Your family member's level of inclusion in the community	3.41 (27)	3.20 (5)	3.76 (25)	3.59 (83)	3.55 (20)	3.60 (248)
Your family member's growth and development	3.50 (26)	3.80 (5)	3.96 (25)	3.90 (84)	3.90 (20)	3.93 (247)
^a Scale: 1 = a lot worse.....5 = a lot better						

Impact of Age of Family Member on Responses

An analysis was conducted to determine if the age of the family member was related to the responses of the family. The age of the family member was divided into two categories: (1) those under 21 years of age; and (2) those over 21 years of age. There was no significant responses based on age (see Table 13).

Table 13. Comparison of Responses by Age of the Family Member^a

<i>Item:</i>	Children/Youth	Adults	Significance
Your family's life overall	2.98 (45)	2.82 (39)	-
Your family's ability to do more together	2.59 (44)	2.61 (38)	-
Your stress in your family's life	2.75 (44)	2.74 (38)	—
Your family's ability to be more like other families	2.68 (44)	2.53 (36)	-
Your ability to care for your family member	2.78 (45)	2.63 (38)	-
Your financial worries	2.64 (45)	2.42 (38)	-
Your worries about your family members' future well being	2.84 (44)	2.47 (38)	-
Your ability to do things that you were unable to do before	2.84 (45)	2.68 (38)	-
Your ability to get to know other people in your community	2.51 (45)	2.42 (38)	-
Your family's level of inclusion in the community	2.49 (45)	2.29 (38)	-
Your family's emotional well being	2.71 (45)	2.70 (37)	-
Your family's physical health	2.42 (45)	2.41 (37)	-
Your family members' emotional well being	2.73 (45)	2.58 (38)	-
Your family members' level of inclusion in the community	2.64 (45)	2.43 (37)	-
Your family members' growth and development	2.82 (45)	2.39 (38)	-
^a Scale: 0 = a lot worse.....4 = a lot better			

Impact of Signed Agreement on the Family Member Responses

A separate analysis was conducted comparing those who had a signed agreement and those who did not. In this comparison, there were many significant differences between the two categories. Those with a signed agreement reported a more positive impact of the program than those who did not have the agreement (see Table 14).

Table 14. Comparison of Responses by Presence of Signed Agreement^a

Item:	No Plan Signed	Plan Signed	Significance
Your family's life overall	2.50 (12)	3.05 (83)	p=.091
Your family's ability to do more together	2.27 (11)	2.77 (81)	p=.112
Your stress in your family's life	2.18 (11)	2.95 (81)	p=.072
Your family's ability to be more like other families	2.36 (11)	2.76 (79)	p=.155
Your ability to care for your family member	2.09 (11)	2.90 (82)	t(df=13.008)=3.03, p=.010
Your financial worries	1.82 (11)	2.74 (82)	p=.056
Your worries about your family members' future well being	2.09 (11)	2.90 (81)	t(df=14.118)=3.515, p=.003
Your ability to do things that you were unable to do before	2.09 (11)	2.94 (82)	t(df=11.590)=2.595, p=.024
Your ability to get to know other people in your community	2.27 (11)	2.67 (82)	-
Your family's level of inclusion in the community	2.00 (11)	2.55 (82)	p=.106
Your family's emotional well being	2.00 (11)	3.16 (81)	t(df=19.977)=2.54, p=.019
Your family's physical health	1.73 (11)	2.59 (81)	t(df=12.509)=2.999, p=.011
Your family members' emotional well being	2.00 (11)	2.71 (82)	p=.062
Your family members' level of inclusion in the community	2.09 (11)	2.58 (80)	p=.129
Your family members' growth and development	2.09 (11)	2.63 (81)	p=.182
^a Scale: 0 = a lot worse.....4 = a lot better			

Five items were significantly different when comparing this category. The families felt that they could care for their family member better if they had a signed agreement. The mean responses were 2.90 for the families with the signed plan and 2.09 for those without. The families with the signed plan worried less about the future well being of their family member than those who did not. In addition, families with a signed agreement felt that they were able to do things they could not do before the plan was signed. The means for these items were very similar.

The families with signed agreements felt that their emotional and physical well being had improved since participating in the Family Directed Support program. Regarding emotional well being, the mean for those who had signed agreements was 3.16 and the mean for those without was 2.00. For the family's physical health, the mean for the former group was 2.59 and for the latter, 1.73.

Other Issues or Events that Impact the Family's Life

One question asked the families to identify other issues that impacted their family's life. This item was interpreted differently by many of the respondents. Many felt that it was related to the program and merely said, *Thank you!* or *The program is great. I would recommend it to all.* Many others reported about their own personal life or that of their child. This section will describe the subjective responses to this question.

Positive Responses

There were many responses that were quite positive about the program and did not discuss other issues or events that impacted the family's life. Some of those responses are listed here.

- *We are talking more as a family. We do more things together as a family. ...is growing up so much and the bond in the family is stronger. We are very happy to have home.*
- *... is building trusting relationships with the support staff and likes them. He enjoys being around them. The support person can take ...out into the community for activities.*
- *The Family Directed Support Program has allowed us to begin ...'s applied behavioral analysis program,. Our school district is only paying for 2/3 the cost of the program. This program (FDS) has been an essential tool in getting this programming (ABA) started forhas been in his ABA program for only six weeks and we have seen a change.*
- *The Home Health program we are getting for ... has been a tremendous help for all. ...is doing a great job getting everything in order to help our family. Thank you.*
- *...is now a tax paying citizen. Communication therapy will enable him to be successful in college and employment.*
- *Her program through the family supported services has given her the inclusive opportunity to experience a wide variety of eight summer half-day voluntary work environments right within our local community so that we can plan for high school and assess through experience what kinds of work she actually likes. Jobs with resumes and interview experience were specifically found in response to her individual interests. The ... county location also may acquaint our community with the possibilities of contributions people like ... can make and "prime" out community for her later personal paid employment. This summer experience will hopefully lead to summer paid employment next year, just like her older brothers and sisters.*

Issues with Support Staff

While the Family Directed Support Program was seen as helping many aspects of the family's life, there were some new issues related to support staff.

FDS has been great for ... and the family. I think we are still realizing how her attendant care is freeing us up to come and go more normally. However, along with the freeing up seems to come the new headache of quickly changing support staff and scheduling issues. With time, hopefully this will flow more evenly.

There appeared to several people to be a *lack of respite care providers*.

One family's issue with a support staff was with the agency that hired the staff. *The thing we are having a lot of trouble with is getting an attendant care agency to hire an aunt and cousin, even though I know they legally can. I am told they don't have enough experience, even though they have helped me care for ...for ten years = Help!*

Transportation

Transportation has been an issue for many years for families and consumers in the Missouri Department of Mental Retardation/Developmental Disabilities. It continues to plague many families. There were a number of responses related to transportation. *Transportation - no one to provide service.* Another family stated *we still have problems getting a social life. Also, getting a ride to junior college.* For yet another, *need transportation with a lift.* For one family who was able to receive transportation, the difference was great. *Transportation - it frees up our day. Transportation - we needed this for years.*

Timelines of Signed Agreement

Some of the families saw the process of obtaining a signed agreement as taking too long. *This has been great since it finally got started - it took way too long to happen. Her plan was done in December 1998 and it took until April 1999 to start. But now it is going - it's wonderful - it has relieved a lot of stress and has helped our family as a whole.* Another family echoed this response. *It took entirely too long to have ...'s Family Directed Support program approved. My stress level went off the charts not knowing where he was going to be after graduation.*

Financial Assistance

One family wanted financial assistance for their daughter. *Would be helpful to get a check for our daughter to spend as we like.* A few families reported having *financial worries*. Some families listed what they wanted the financial assistance for. *Financial support to attend National Autism Symposium in St. Louis. Financial assistance for respite.* Another family wanted assistance with *diapers*.

Some families had personal financial issues that went beyond the family member. *My daughter has leukemia and Down Syndrome. I am recently separated and will be divorced soon. I need to find employment and still take care of my four kids. My ex-husband lost his job and works part-time now. My daughter's leukemia has put great stress on all of us. I have had my daughter fully included and will probably have to change schools next year.* A similar case was *Finances are tight because I am the only one able to work. There are six people in my family and one of them is disabled. He could not go to library to use computer so I really want to buy one for him, but it is out of my hands.*

For some families, it is not financial worry that was the issue, but rather guarding their funds for their family member. *...stated she does not currently have a long-term life plan in place (estate planning,*

trusts, etc.) but would like to focus on it as soon as some of the other things are in place. A second family echoed this concern. *I need to research some more on estate planning.*

Learning About Resources

For one family, knowing what is available to help them was still a mystery. They wanted more assistance in learning about potential resources. *We may be interested in home respite care, home modification, enabling...to have more independence. I guess we need a little more help finding out what is available. To help ...live on his own. We are well pleased with the help we are getting with transportation.*

Flexibility of Program

The program was seen as needing to continue to be flexible and changing. As one person reported, *I hope the program's flexibility will continue to grow as my needs for my son have changed quite a bit just since my initial training and involvement with the program.*

Lack of Follow-Through

Some families reported that while there were plans in place, there was a lack of follow through on carrying out the activities of the plan. *There are some issues and concerns that were discussed at the planning meeting that have not been followed through on (e.g. bathroom modifications and adaptations for ... to use the shower). Guardianship issues are also a concern, although Mom says she tries not to think about it. Guardianship info is written into the plan.*

Health Issues

There were a number of responses that indicated that the family had health issues either of the child or a family member. Some merely stated health issues. *For one family, their situation was worse, not because of the program, but because of health. One person said age issues. Health issues can change a living situation and cause a lot of stress. My husband and I both have heart problems and have been told we can no longer keep... at home. The stress issues and emotional issues this causes has not helped our situation.*

For some families, the health issue was with their family member. These families were faced with many concerns. *We are dealing with a terminal medical condition of our daughter, so we constantly have to fight to keep going and keep our spirits up.*

Public Awareness

A need was seen for more public awareness on the part of the public, be it teachers or social workers. *Sometimes people look at my children and think they are fine and nothing is out of the ordinary, but refuse to accept that they have some limitations and that makes for a hard time of understanding on their part. It affects their self-esteem. In school we have staff such as a social worker and school nurse who don't take time and investigate things before Child Services are called.*

Community Activities

For some families, community activities were lacking in their son or daughter's life. *They would also like to see him have something to do: during the day. Currently there is nothing available for their son to do during the day. For one person, funding was lacking to allow community employment. ... wants to work, but because of transportation, funding, and no job coach, ... has been sitting watching TV or asking me to take him somewhere.*

Transition

Some families worried about the transition of their child when they aged. *Because ... parents are aging, they would like to see her be able to move out on her own with supports in the next five years or so. They do not want her "forced" into a different living situation/environment due to an unforeseen event with them (illness, death, injury, etc.). They would like to see her have a smooth transition into supported living in the future. Another family had the same concern finding a facility and assistance to help in ... care because of advancing age.*

Home Modification

Several families reported issues related to home modification. For one family it was *home remodeling for accessibility*. For another, it was *need of labor for a fence, an alarm/lock system for the home, a computer and software for learning*. *They would also like to talk more with other families.*

Support Services

There was a stated need for support services in home OT and speech therapy. *Support getting ... to become a full-time student in the ...(public education).*

Internet Access

One family noted how much access to the Internet had helped her family. *Another helpful resource has been being on a CHARGE list on the Internet. It has enabled me to talk with other parents of children with CHARGE.* Other families reported this as a need. *Would like to see families have access to web site for sharing valuable resources, networking, etc.*

Summary

A pilot outcome of families who received services under the Missouri Division of Mental Retardation/Developmental Disabilities Family Directed Support Program showed the following as a result of this program:

- Over 55% of respondents perceived their ability to care for their family member as improved.
- Over 65% of respondents reported being better able to do things they were unable to do before.
- Family well being improved for over 60% of families, and the family members' emotional well being improved by 50%.
- The age of the family member was not related to improved quality of life, but whether the plan had been signed was.